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ABSTRACT

This project report presents findings on the implementation and progress of the On the Right Track program during the second year of a four-year grant period. The project, which began in July of 1997, is designed to assess and document the magnitude, severity, and secondary conditions of disabilities for persons with disabilities in Texas, to promote healthy lifestyles for people with disabilities in Texas, and to strengthen the leadership role of the Texas Department of Health in this domain. The report provides an overview of key features of the On the Right Track program and outlines the roles and responsibilities of program partners. It briefly describes implementation during year two and presents project constraints and lessons learned. Findings from the project include the following: (1) progress has been made with respect to the state-level data review, the Behavioral Risk Factor Surveillance System-Disability Module, and injury surveillance activities during year two; (2) numerous health promotions have occurred; (3) the release of funding to certain project partners was cited as a constraint during year two of the project; and (4) the state strategic plan for the prevention of secondary conditions was completed. (CR)

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Year Two Evaluation:
On the Right Track

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Executive Summary

The Ray Marshall Center for the Study of Human Resources of the Lyndon B. Johnson School of Public Affairs at The University of Texas-Austin prepared this evaluation report for the Texas Department of Health's *On the Right Track* project sponsored by the Center for Disease Control and Prevention. This report presents findings on the implementation and progress of the *On the Right Track* project during the second year of a four-year grant period.

Researchers conducted face-to-face interviews with members of the project staff as well as various project partners affiliated with *On the Right Track*. Program documentation was also extensively reviewed for this evaluation.

The report provides an overview of key features of the *On the Right Track* project and outlines the roles and responsibilities of project partners. It briefly describes the implementation of the project during Year Two and subsequently presents project constraints and lessons learned during its implementation phase.

Key *On the Right Track* Features

The project, which began in July of 1997, is designed to:

- Assess and document the magnitude and severity of disabilities and secondary conditions for persons with disabilities in Texas.
- Promote healthy lifestyles for people with disabilities in Texas
- Strengthen the leadership role of the Texas Department of Health (TDH) in this domain.

The Texas Department of Health is partnering with a number of organizations including, but not limited to, the Houston Independent School District (HISD), Baylor College of Medicine, the Temple Independent School District (TISD), Scott & White Medical Center, the Texas Office for Prevention of Developmental Disabilities (TOP)/*On the Right Track* Advisory Committee (ORTAC) and the following divisions within TDH - Research and Public Health Assessment, Behavioral Risk Factor Surveillance System (BRFSS), and the Bureau of Epidemiology .

Key findings to date include the following:

- Progress has been made with respect to the State-level data review, the Behavioral Risk Factor Surveillance System (BRFSS) – Disability Module, and injury surveillance activities during Year Two.
- There were delays in the implementation of the research projects in Harris and Bell counties due to programmatic (Institutional Review Board approval) and collaboration constraints.

- Numerous health promotion activities occurred during the latter part of Year Two following the hiring of a Program Specialist in April of 1999.
- The release of funding to certain project partners was cited as a constraint during Year Two of the project.
- The State Strategic Plan for the Prevention of Secondary Conditions was completed and plans for its dissemination are currently underway.

1. Introduction

Researchers at the Ray Marshall Center for the Study of Human Resources of the LBJ School of Public Affairs at The University of Texas at Austin conducted a retrospective evaluation of Year 2 activities for the Texas Department of Health's *On the Right Track* project sponsored by the Center for Disease Control and Prevention (CDC). The evaluation was designed to describe the implementation of the project and to assess its overall progress toward project goals. The results are used to identify accomplishments and to address gaps and make improvements where necessary.

1.1. *On the Right Track* Project Overview

The staff at the Texas Department of Health (TDH) designed the project to address the prevention of secondary conditions for persons with disabilities in Texas. The project has four main goals:[1]

- To assess the magnitude and severity of disabilities and secondary conditions.
- To promote healthy lifestyles for people with disabilities in Texas by increasing awareness of the need to prevent secondary conditions within the learning domain among consumers, providers, and policy makers.
- To strengthen the leadership role of the Texas Department of Health in the understanding of and prevention of secondary conditions associated with disabilities in the learning domain.
- To evaluate project activities.

A 1994 report, by the Texas Senate Committee on Health and Human Services, highlighted the gaps in services and information available to Texans with disabilities. TDH project staff utilized this information in the design of *On the Right Track* and expect some of the following benefits from its implementation.[2]

- Improved ability by the state to collect and analyze available data from various organizations related to secondary effects of disabilities on learning.
- Increased understanding of disabilities in Texas and their impact on individuals.
- Determination of the incidence and prevalence of disabilities in the learning domain and their associated secondary conditions and protective factors.
- Training of physicians, nurse practitioners, managed care organization medical directors, and care coordinators in the early identification of disabilities in children.

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[1] TDH, Project Workplan: Goals, Objectives, Activities, Schedule, and Staff, 1998, pg. 20-25.
[2] TDH, *On the Right Track* Grant Application: Preventing Secondary Disabilities in Texas, 1997, pg. 31-32.

- Implementation of effective health promotion and technical assistance activities for consumers, family members, service providers, state agency staff, and policy makers on the prevention of secondary conditions.

1.2. Evaluation

1.2.1. Year-One (July 1997-June 1998) Evaluation

An evaluation of the progress of the *On the Right Track* project for activities encompassed within Year One of the grant period was conducted by the University Affiliated Program (UAP) at The University of Texas at Austin.[3] UAP utilized a "template" methodology for the evaluation of Year One efforts. A template methodology is useful for understanding the history of an evolving program.[4] The evaluation examined:

- Year-One *planned* activities as detailed in the work plan
- Year-One *actual* activities
- Reasons for departure of *planned* and *actual* activities

Based on the review of the highlighted planned versus actual activities encompassed under Goal 1 of the project, there was progress made with respect to the review and analysis of existing data sets from other state agencies and organizations, the implementation of the Behavioral Risk Factor Surveillance System (BRFSS) - Disability Module, and the surveillance of condition-specific data. However, they found a gap between the two areas (planned versus actual) concerning the research projects in Harris and Bell counties. The Bell county project was not part of the original design of the project but evolved later in Year One which accounts for the delay in completion of these activities. In addition, UAP concluded that inadequate time was budgeted for the completion of the NIH IRB process for the Harris county research project.[5]

Goal 2 of the project centered around the promotion of healthy lifestyles for people with disabilities. Progress was made in the following areas:

- A final evaluation report was submitted concerning the *Caring for Infants and Toddlers* (CFIT) model for physician education.
- Existing education and training programs that provided quality didactic and practicum experience were identified and, due to the quality of the existing programs, the development of a new model curriculum was forgone.
- Health promotion activities (e.g., poster displays, training, newsletters, etc.) in the area of Fetal Alcohol Syndrome (FAS) as well as a presentation at the March of Dimes National Seminar were completed.

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[3] UAP is under contract with TDH to perform various activities for the *On the Right Track* project.
[4] UAP: Year 1 Evaluation Report, 1998, pg. 1.
[5] Ibid.

- A prototype of the TDH Bulletin Board System (BBS)/World Wide Web (WWW) site was developed.

Planned activities for which there was no activity or the activity was changed included:

- Implementation and data analysis of the health promotion program for Harris County.
- Design, implementation, and dissemination of health promotion information targeted for state agency staff, legislators and other policy makers.
- Utilization of teleconferencing/telemedicine for education/training of health care providers and school personnel.

The activities under Goal 3 concerned the strengthening of the leadership role of the Texas Department of Health in the understanding of and prevention of secondary conditions associated with disabilities. Accomplishments in this area for Year One included:

- Establishment of a Project Advisory Committee.
- Collaboration between the Project Advisory Committee, the Texas Office for the Prevention of Developmental Disabilities (TOP) and other groups (e.g., Children with Special Health Care Needs).
- Initial design of a Statewide Strategic Plan for Prevention of Secondary Conditions in the Learning Domain.

Objectives not completed during Year One included:

- Development of TOP and TDH staff knowledge base through health promotion/awareness information.
- Establishment of on-line technical assistance through the TDH-BBS and TENET (the Texas Education Agency's telecommunications network).

The final goal of the project, evaluation of project activities was met through the UAP office.

1.2.2. Year-Two (July 1998-June 1999) Evaluation

The staff at the Ray Marshall Center performed a retrospective analysis on the Year 2 activities for the *On the Right Track* project. Key topics and primary research questions for the evaluation are:

- **Program design and implementation**. What are the components of the project and how are these components being implemented?
- **Activities and services**. What is the range of activities and services being planned for the prevention of secondary conditions among people with

disabilities in Texas, the promotion of healthy lifestyles, and the strengthening of leadership efforts?

Researchers from the Ray Marshall Center monitored the implementation efforts of the research projects in Temple and Houston in addition to examining the progress on Goals two and three of the study. Interviews at both research sites were conducted with project partners and program documentation was reviewed.

1.3. Organization of Text

Section Two presents key features of the *On the Right Track* project and roles and responsibilities of collaborating agencies. Section Three explores project implementation and identifies accomplishments, barriers and lessons along with suggestions for addressing gaps where they exist. Section Four highlights the program's objectives, anticipated outcomes of the project, as well as other observations made by the evaluation team. Finally, it also offers a brief description of the evaluation efforts planned for Year Three of the project.

2. Key Features of the *On the Right Track* project

The *On the Right Track* project addresses four main goals: Science, Service, Leadership, and Evaluation. This section examines, in more detail, each of these goals.

2.1. Science

This project goal seeks to assess the magnitude and severity of disabilities and secondary conditions in Texas. In order to accomplish this goal, a number of objectives were defined to meet them.

2.1.1. Research Projects

Two research projects were designed to help address the first goal of this project. One project, in Harris County (Houston), involves the use of telemedicine among educational and medical providers as well as the children with disabilities and their families. Telemedicine is the transfer of electronic medical data (i.e., high resolution images, sounds, live video, and patient records) from one location to another.[6] In this project, members of T.H. Rogers School in Harris County are partnering with The Meyer Center for Developmental Pediatrics at Baylor College of Medicine/Texas Children's Hospital to provide this service to students and families at the school. T.H. Rogers serves three populations of children: 1) gifted and talented; 2) profoundly deaf, and; 3) children with multiple disabilities. The school has had an on-going relationship with the Meyer Center for the past 4-5 years whereby a doctor, and at times interns, provide consultation for teachers and parents regarding the medical conditions of various children. Telemedicine is now being explored as a means to facilitate school access to medical consultation and to reduce transportation time and cost related to the consultation.

[6] See http://208.129.211.51/WhatIsTelemedicine.asp.

The second research project, in Bell County (Temple), is examining the effects of Family-Centered Planning for children with disabilities and their families. The Temple Independent School District (ISD) is partnering with Scott & White Medical Center on this project. The main goal of the project is to create multidisciplinary, collaborative teams (including educators, health care providers, and families) to address the needs of children and their families. Team facilitators and planning software are at the core of this project. The team facilitator will mediate interactions and information sharing among the different members of the team while the planning software represents cutting-edge technology in the domain of health care and educational planning.[7]

2.1.2. State Level Data Review

The purpose of this portion of Goal One is to assess the availability and accessibility of existing data sets from national and state agencies regarding data on secondary conditions. This objective seeks to standardize data resources and provide coherent statistical information for policy makers.[8] In addition, a new activity to emerge from the process is the development of a state-wide Quality-of-Life survey to assess the incidence and prevalence of primary disabilities and related secondary conditions.[9]

2.1.3. Behavioral Risk Factor Surveillance System (BRFSS) – Disability Module

Another objective under Goal One is to continue the use of the BRFSS to determine the severity of disabilities and secondary conditions in Texas.[10] The BRFSS is a country-wide surveillance system which collects information on adults' attitudes, behaviors, and practices related to many risk behaviors. The BRFSS serves as the primary source of state-based information on behaviors such as tobacco use, diet, and those which impact women's health. Initiated in 1980, the questionnaire is administered monthly via telephone interviews.[11] TDH has been able to incorporate disability questions on the survey.

2.1.4. Injury Surveillance

This objective serves to assess condition-specific surveillance and epidemiological activities. The specific conditions being examined include, but are not limited to, Traumatic Brain Injuries (TBIs), Spinal Cord Injuries (SCIs), and submersions/near drownings as well as injury clusters around these conditions.

2.2. Service

This portion of the larger *On* the Right Track project serves to promote healthy lifestyles for people with disabilities in Texas by increasing awareness of the need to prevent secondary conditions.[12] Specific objectives under this goal include:[13]

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[7] TDH, Section 2: New Budget Year Work Plan (7/1/1999 – 6/30/2000), pg. 20).
[8] TDH, Section 2: New Budget Year Work Plan (7/1/1999 – 6/30/2000), pg. 23).
[9] TDH, Section 2: New Budget Year Work Plan (7/1/1999 – 6/30/2000), pg. 24).
[10] TDH, Year 2 Application, pg. 15.
[11] See http://www.outcomes-trust.org/sp97/cps3.htm
[12] TDH, Year 2 Work Plan Revised.

- The evaluation and subsequent state-wide implementation of the Caring for Infants and Toddlers (CFIT) model for physician education and training.
- The development of a "single point of access" for education and training of health care providers, educators, and consumers on the TDH website.
- The development of "broad-based" health promotion activities such as a catalog/compendium of resources, brochures, fact sheets, etc., for consumers, family members, and service providers.

2.3. Leadership

This goal serves to strengthen TDH's leadership role in the understanding of and prevention of secondary conditions associated with disabilities in the learning domain. The objectives under this goal involve:[14]

- Increasing the visibility of the *On the Right Track* Advisory Committee (ORTAC) and the Texas Office for the Prevention of Developmental Disabilities (TOP) through the partnering of these groups with consumers, state agencies, and disability service organizations.
- Distributing the Statewide Strategic Plan for the Prevention of Secondary Conditions to other state agencies and disability organizations to help promote healthy lifestyles among this population.
- Providing technical assistance to disability service organizations, vulnerable populations, and community groups.

2.4. Evaluation

An on-going evaluation of project activities was also included in the design of the project. The major objectives were to develop an evaluation methodology for programs and activities relating to the first three goals of the project: (e.g., Science, Service, and Leadership), and then to conduct evaluations of those activities.[15]

2.5. Roles and Responsibilities of Collaborating Agencies

The *On the Right Track* project was highly collaborative in nature and design. Numerous organizations and agencies voiced interest in the project from the beginning and the smaller proportion who have become primary partners are described.

University Affiliated Program (UAP). During Year 2, the UAP was contractually responsible for the implementation of the research projects in Harris and Bell counties. In addition, they were responsible for the Statewide Strategic Plan for the Prevention of Secondary Conditions.[16]

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[13] Ibid.
[14] Ibid.
[15] Ibid.
[16] TDH, Year 2 Application, pg. 34.

Houston Independent School District (HISD). The school district, specifically T.H. Rogers School, is serving as the educational site for the telemedicine project in Harris County. The school serves profoundly deaf as well as students with multiple disabilities. The school has a well-established relationship with another of the project partners, The Meyer Center at Baylor College of Medicine. Staff at the school have been trained in the use of the telemedicine technology and will facilitate its implementation.

The Meyer Center for Developmental Pediatrics at Baylor College of Medicine/Texas Children's Hospital. This project partner has a well-established telemedicine program and relationship with the educational site for the research project, T.H. Rogers. Doctors and interns from the Center have been consulting on-site at the school for over 4 years and are looking to utilize the technological advances in the medical field, specifically telemedicine, to facilitate the provision of services.

Temple Independent School District (TISD). The school district, specifically the Department of Special Education, is collaborating on the Family-Centered research project in Bell County. It is anticipated that teachers at the school will collaborate with the medical provider, Scott and White Medical Center, to provide family-centered planning for the children and their families.

Scott & White Medical Center. This partner is serving as the medical liaison for the research project in Bell County. Staff at the site will serve on the "team" along with family members and educational providers in order to deliver comprehensive services to the children who are selected to participate in the project.

Texas Department of Health; Research and Public Health Assessment Division. Two staff members from this department are the leads on the State Level Data Review. These partners have collaborated with numerous state agencies, affiliated organizations, as well as Federal offices in the identification and collection of data on disabilities, specifically relating to secondary conditions. In addition to data gathering and examination, this office will implement a survey on Quality of Life issues surrounding the prevention of secondary conditions for those with disabilities in Texas.

Texas Department of Health; BRFSS Division. The Director of the division is collaborating with the project coordinator on the data collection efforts of the BRFSS. The survey, in Texas, added disability questions as requested by the CDC. The division will provide survey results through the duration of the grant to the project coordinator.

Texas Department of Health; Bureau of Epidemiology. Two staff members in the department are conducting the surveillance activities related to the project. The activities have focused on three surveillance areas: 1) traumatic brain injuries (TBIs); 2) spinal cord injuries (SCIs) and; 3) submersions/near drownings. The staff are providing the project coordinator with data relating to these conditions in Texas.

Texas Office for Prevention of Developmental Disabilities (TOP)/On the Right Track Advisory Committee (ORTAC). The Advisory Committee was created by adding three consumer members to the existing nine-member TOP executive committee.[17] Advisory committee members are collaborating with TDH to enhance the understanding of and prevention of secondary conditions through partnerships with consumers, state agencies, and disability service organizations.

3. Project Implementation

This section describes processes and procedures associated with Year-Two implementation of the *On the Right Track* project. The text briefly presents principal features of Year-Two activities and discusses barriers that were encountered, as well as lessons that might be learned from the experiences of project partners and staff.

3.1. Science

3.1.1. Harris County (Houston) Telemedicine Project

3.1.1.1. Methods

Researchers conducted face-to-face interviews with project partners, UAP and TDH staff during June 1999. These one-on-one conversations with the different participating entities permitted researchers to develop an understanding of program implementation issues. The interviews were designed to probe the levels of involvement of the entities and their roles in the project for Year Two. Researchers collected and reviewed *On the Right Track* documentation (including project plans, memoranda, and reports) in support of the field work.

3.1.1.2. Time Frames

Preparations for the implementation of the research project in Harris County began in 1997 and continued through the end of Year Two. The original Year-Two Work Plan had the research project being implemented during Year Two however, the revised plan changed the objective to encompass capacity-building activities for the project instead. The estimated time frame for the implementation of the research project is Fall of 1999.

3.1.1.3. Pre-implementation preparation

Planning. Advance planning and design sessions were led by the TDH project team. The Harris County project partners: (UAP, T.H. Rogers, and Baylor College of Medicine) examined and provided input/suggestions on the project's design and implementation plan. Both formal and informal contact occurred during Year Two of the grant.

[17] TDH, Year 2 Application, pg. 8.

Training. Technical training on the telemedicine technology was provided to staff at T.H. Rogers by Jim Shanahan from the Center for Telemedicine at Baylor College of Medicine during the Fall of 1998.

Organization/Staffing Patterns. During Year Two, staff at T.H. Rogers helped design the job description for an administrative/support staff person who is needed in order to implement the telemedicine project at the school. Dr. Reynolds, the developmental pediatrician from The Meyer Center, who has been consulting on-site at the school for the last couple of years, will continue her involvement via the telemedicine link.

Funding. The Year-Two budget included funding for five percent of Dr. Reynolds' salary to support her continued participation in the process. In addition, funding is budgeted for the administrative/support staff member at T.H. Rogers to coordinate activities with the parents. To date, no expenditures have been made by TDH for either of these activities.

3.1.2. Bell County (Temple) Family-Centered Research Project

3.1.2.1. Methods

Researchers conducted face-to-face and telephone interviews with project partners and UAP and TDH staff during June 1999. The purpose of these interviews was identical to that for the Harris County research project – to develop an understanding of research implementation issues. As with the Harris County project, researchers collected and reviewed relevant documentation (including project plans, memoranda, and reports).

3.1.2.2. Time Frames

The Bell County project was not in the original proposal submitted to the CDC and was added approximately six months into the first year of the *On the Right Track* project grant period. As with the Harris County research project, the original Year-Two Work Plan had the project being implemented during that year, however, revisions were made that changed the objective to encompass capacity-building activities for the project instead. The estimated time frame for the implementation of the research project is Fall of 1999.

3.1.2.3. Pre-implementation preparation

Planning. Planning and design sessions were led by the TDH project team with input from the Bell County project partners: UAP, Temple ISD, Scott & White Medical Center, the Children's Special Needs Network, and TDH regional staff. Both formal and informal communication took place during Year Two of the grant.

Training. It is anticipated that technical training will be required for the planning software that has been developed as part of the Family-Centered

Planning model. Technical assistance will be provided by Paul Davis from Database City. Training will also be required for the team facilitator who will be hired to coordinate activities among families, educational providers, and the medical liaisons at Scott & White Medical Center. This training will be completed and administered by TDH staff

Organization/Staffing Patterns. A specific job description has been prepared for the *Lead Facilitator* position in Bell County. This individual will manage the local activities of the project. A general job description has been developed for the *Team Facilitators* who will serve as advocates for the collaborative, family-centered model of planning.[18]

Funding. The Year-Two budget included funding for support staff time at Scott & White as well as the school district for organizational activities related to the project. Funding was shifted to pay facilitators and administrative support for the project; no longer Scott and White staff. No expenditure has been made to date. In addition, funding was provided to Dr. Carl Dunst for his expertise and consultation regarding the Family-Centered Planning Model.

3.1.3. State Level Data Review

3.1.3.1. Methods

Researchers interviewed the project coordinator and the two TDH staff members assigned to this portion of the project during June 1999. *On the Right Track* project documentation was also reviewed to further inform the evaluation.

3.1.3.2. Time Frames and Activities

Staff members in the Research and Public Health Assessment Division of TDH have been active project participants since the inception of the grant in 1997. Their participation has remained constant over the first two years of the grant and is expected to continue through the duration of the grant. Activities addressed during Year Two of the grant included:

- A review of the Social Security Administration's data on disabilities and the steps needed for acquiring the data were identified and implemented.
- The implementation of ad hoc queries to other state and federal agencies concerning disability data relating to secondary conditions.
- An in-depth examination of four state databases: Public Education Information Management System (PEIMS), Mental Health and Mental Retardation (MHMR), Medicaid, and Chronically Ill and Disabled Children's Services Program.

[18] TDH, May 5, 1999 document to Lisa Garbarino, pg. 21.

3.1.4. Behavioral Risk Factor Surveillance System (BRFSS) – Disability Module

3.1.4.1. Methods

Researchers relied on an interview with the project coordinator and program documentation to evaluate the progress of BRFSS – Disability Module activities.

3.1.4.2. Time Frames and Activities

The BRFSS was conducted during Year Two of the grant. Summary tables for Texas were submitted to the project coordinator in March of 1999 and monthly data collection will continue. Participation in the project is anticipated to continue through Year Four.

3.1.5. Injury Surveillance

3.1.5.1. Methods

Researchers relied on an interview with the project coordinator and program documentation to evaluate the progress of the injury surveillance activities.

3.1.5.2. Time Frames and Activities

Staff members in the Bureau of Epidemiology at TDH have been active project participants since 1997. As with the other TDH affiliated staff, their participation has remained constant and is expected to continue through Year Four of the grant. A sample of activities addressed during Year Two of the grant included:

- Analysis of DPS data
- Analysis of mortality and morbidity data for bicycle-related injuries
- Report matching for TBI cases between Trauma Registry and Bureau of Vital Statistics
- Analysis of Travis County bicycle-related injuries
- Analysis of 1997 mortality data by Trauma Service area
- Motorcycle traffic-related injuries
- Implementation of new submersion form

3.2. Service

3.2.1. Caring for Infants and Toddlers (CFIT) Model

3.2.1.1. Methods

Researchers relied on an interview with the project coordinator and program documentation to evaluate the progress of CFIT activities.

3.2.1.2. Time Frames and Activities

TDH contracted with UT Southwestern Medical Center and Scottish Rite Hospital in Dallas Texas to conduct the CFIT physician education and training during Year One of the grant. The pilot test was conducted during March-April of 1998, and a final report was submitted to CDC project officers.

Two follow-up trainings were conducted during Year 2. The first was conducted in May of 1999 where 130 pediatricians attended and the second was held in June of 1999 where 50 family practice physicians attended. A meeting was held on June 14, 1999 between members of the CFIT team and the Interagency Council on Early Childhood Intervention (ECI) to continue coordination efforts for the state-wide rollout of the CFIT model.

3.2.2. Health Promotion Activities

3.2.2.1. Methods

Researchers relied on an interview with the project coordinator and program documentation to evaluate the progress of the health promotion activities.

3.2.2.2. Time Frames and Activities

A TDH Program Specialist was hired in April of 1999 and activities completed between April and June include:

- Development and printing of two program brochures: "*On the Right Track*" overview and Texas Strategic Plan.
- Update of display board materials.
- Attendance at the Texas Education Agency Summer Institute for teachers and school staff in June of 1999. Display board, brochures, and other TDH program information was distributed.
- Ordering of promotional materials for future presentations, conferences, training sessions, and research project participants completed.

In addition, the *On the Right Track* website is available as a TDH test site and is not yet accessible to the public. Once beta-testing has been completed by a range of agency staff, the site will be made available to those outside of TDH.

3.3. Leadership

3.3.1. *On the Right Track* Advisory Committee (ORTAC) and the Texas Office for the Prevention of Developmental Disabilities (TOP)

3.3.1.1. Methods

Researchers relied on an interview with the project coordinator and program documentation to evaluate the progress of activities under this objective.

3.3.1.2. Time Frames and Activities

A joint meeting of TOP/ORTAC was held during Year One of the grant, and visibility of the ORTAC increased with attendance at meetings held by other advisory committees (e.g., TDH Children with Special Health Care Needs Advisory Committee). An ORTAC meeting was held in February of 1999 where discussions about the Strategic Plan centered on details for the appropriate promotion and dissemination of the plan within various communities. There was another meeting of ORTAC in May of 1999. The project coordinator participated, twice, in the hiring process for the Executive Director position of TOP. Partially due to this vacancy and TOP's inability to hold a quorum, TOP/ORTAC meetings were infrequently scheduled or cancelled just prior to the meeting date.

3.3.2. State Strategic Plan for the Prevention of Secondary Conditions

3.3.2.1. Methods

Researchers relied on an interview with the project coordinator and program documentation to evaluate the progress of activities under this objective.

3.3.2.2. Time Frames and Activities

Focus groups with parents, consumers, and health care providers were conducted during Year One of the grant in five Texas communities. Data from these focus groups were utilized by UAP to complete the Strategic Plan in January of 1999. Themes for the training of the plan have been drafted by UAP, and plans for the development of a curriculum are underway.

3.4. Project Constraints

Certain barriers were encountered during Year Two of the *On the Right Track* project. Challenges that did arise centered around implementation of the research projects in Harris and Bell Counties, database limitations, staffing, collaboration among partners, and funding issues.

Research projects[19]. As stated previously, the original Work Plan for Year Two had detailed the activities necessary for the implementation of the research projects in Harris and Bell Counties. However, during the course of Year Two, the project partners realized the necessity for enhanced capacity building and revised the Work Plan accordingly. Although capacity building is vital to the project, it has reduced the amount of time that the pilot and final projects may operate which subsequently limits the amount of data that can be collected. This may constrain the range of findings that can be drawn from the research.

In addition, the Institutional Review Board (IRB) approval process has proven challenging for both research projects. The challenge stems from two areas: 1) the need for National Institute of Health (NIH) IRB approval which had not been anticipated during Year One of the grant, and 2) the need to have multiple institutions' IRB committee review and agreement. This additional step has delayed the implementation of the research projects in both sites.

Database limitations. During Year One of the grant, the State Level Data Review team realized that a number of databases were apparently not collecting the information needed to track secondary conditions[20]. The need for data in this area led to plans for the development of a Quality of Life survey in Year Three and administration during Year Four.

Staffing. This barrier relates to key staff not only at TDH but to key vacancies that needed to be filled in order for the research projects to operate. First, the Program Specialist III staff position at TDH, in charge of the health promotions activities, was vacant for a large portion of Year Two; hence the majority of activities under this objective were largely uncompleted. A staff member has been hired, and progress toward addressing these objectives under the Service goal has resumed.

Second, the Harris County partners are ready to begin the telemedicine project but require an administrative/support staff member at T.H. Rogers who cannot be hired until IRB approval has been received from the NIH. There is a pool of qualified candidates, and it is anticipated that the staff person will be hired shortly. However, if the individual is not in place by September-October of 1999, there is a distinct possibility that the project will be delayed yet another year due to administrative rules and requirements of the Houston ISD.

Third, there are facilitator vacancies, lead and team, yet to be filled for the Temple research project. Once these positions have been filled, training will be required for these individuals. Again, there is concern that the positions be filled expeditiously so that implementation will be possible by the Fall of 1999.

Collaboration among partners. Collaboration among multiple entities can be a double-edged sword. Although there are advantages to obtaining the input of multiple

[19] TDH subcontracted with the UAP to complete the activities associated with the research projects during Years One and Two of the grant.
[20] In-kind support of 25% is being provided by the two members of this team.

constituents, soliciting and coordinating this input can be challenging and time consuming.

There were collaboration barriers during Year Two concerning the implementation of the research projects. Most notably, the ability to coordinate schedules for meetings was one of the more prominent barriers encountered by project partners, which in turn affected communication patterns. Specifically, concern was noted about the lack of mutual understanding about the purpose and intent of the research project in Harris County. The concern is that project partners seem to have different understandings or conceptions of what the telemedicine project is slated to accomplish.

In addition, ORTAC has been under-utilized to date. This under-utilization appears to stem from an inability of TOP members to obtain a quorum for meetings as well as geographic constraints on meeting location.

Another collaboration barrier occurring during Year Two involved TDH and UAP[21]. On the one hand, a member of UAP indicated that their departure from the grant occurred for two main reasons. First, the nature of the operating relationship changed from what was perceived as a more collaborative effort to one more hierarchical in nature. The expectations of project reporting and administrative requirements increased beyond this UAP member's capacity or interest. Second, it was felt that the release of funds to complete project activities was not accomplished in a timely manner. On the other hand, TDH staff indicated that UAP had been less than timely in completing their deliverables. The delays revolved around both research project activities and completion of the Strategic Plan.

TDH is currently investigating options to address the activities for which UAP had been responsible. However, UAP's exit from the project could cause further delays for the implementation of the research projects in Harris and Bell Counties.

Funding issues. As just mentioned, timing issues regarding the release of funds to UAP was a contributing factor to their decision to exit the project. Barriers related to the funding of the *On the Right Track* project were mentioned by other project staff as well as partners. The bureaucracy that typically accompanies a grant of this size and duration always presents challenges, and expeditious funding is apparently one of the major ones. However, the project partners may be unwilling to continue exerting time and effort toward activities for which remuneration is limited, lacking, and/or late. This is a constraint TDH project staff must address during Year Three if the project is to succeed.

3.5. Project Lessons

Project staff and partners are working diligently and thoughtfully toward the attainment of the four project goals: Science, Service, Leadership, and Evaluation. Lessons for the project revolve around the following areas:

[21] According to the TDH, the CDC was aware of operating difficulties between the TDH and the UAP but had requested that the TDH continue to pursue their collaborative efforts with the UAP.

Planning. Planning is an iterative process, and all contingencies cannot be addressed prior to implementation. Advance planning by the project staff and partners has assured the timely completion of numerous objectives within the larger, overall goals of the project. Despite these accomplishments, unanticipated issues did arise during both Year One and Year Two of the grant which significantly delayed the completion of certain objectives (most notably the implementation of the research projects).

Project staff have learned about the federal requirements (e.g., NIH IRB approval) of working with a grant of this type which should prove useful for future applications as well as project planning. Also, staff have learned that contracts need to be written with stricter accountability for those partners charged with completing outlined activities. This implies staff also need to have the ability to enforce the terms of the contract which was a barrier encountered by TDH with respect to UAP deliverables during Year Two.

Finally, some project partners articulated the need for additional advance planning by the project staff regarding the goals and objectives of the project. The partners felt that if the goals and objectives of the project had been more clearly defined and articulated at the start of Year One, then project activities may have progressed farther by the end of Year Two.

Communication. The ability of project partners to communicate effectively is vital to a project of this type – one with numerous partners who are geographically dispersed. Project staff and partners have used the past two years to build relationships with each other which have proven beneficial in many areas. However, there appear to be certain gaps in this area deserving of attention.

Some partners are unclear about their expected role in the project. They have attended various planning meetings and have contributed information but are wondering at the end of Year Two what is expected of them. It is recommended that project staff make a concerted effort to delineate and communicate the roles and expectations of each project partner.

In addition, as previously mentioned in the constraint section, concern was articulated by a Houston project partner regarding the level of understanding about the design and purpose surrounding the telemedicine project. Part of the difficulty may stem from an inability to get all partners to the table – an issue mentioned by a few of the project partners. Another reason for the lack of mutual understanding may involve agreements or terms of participation that were agreed upon by a member of the Meyer Center for Developmental Pediatrics who is no longer part of the project team. This individual apparently contacted each of the Houston project partners and solicited their participation. With the departure, some partners are unclear about what agreements were previously made. It is recommended that project staff spend time reviewing roles and responsibilities with each partner so that any gaps can be addressed before implementation.

Funding. There are certain aspects of a project not under the direct control of staff and unfortunately for TDH this lack of control has resulted in certain consequences. The delayed release of funds was mentioned as a factor in the UAP's decision not to renew their contract with TDH.

In addition, there is an apparent disparity among those receiving financial support for their services. The expectation that professionals will continue to provide time and resources without remuneration may prove even more costly over the duration of the project. It is recommended that project staff review their compensation plan for the services provided by the professionals in their projects and attempt to address gaps where they exist.

The final lesson from Year Two of the project revolves around both communication and funding. An apparent gap exists between the budgeted figures for the Houston project and the reimbursement expectations of the Houston project partners. The evaluation team was unable to identify, in the Year Two budget, if and how the Houston project partners were to be compensated for certain aspects of the computer outlay for the telemedicine project. The expectation exists that some funding will be provided, however, the budget for such expenditures was not identified by researchers at the Ray Marshall Center and no funding has been released to the partners as of June 1999[22].

4. Summary and Final Comments

4.1. Program objectives and Outcome Expectations

Year Two found staff and project partners actively addressing the following objectives:

- The implementation of capacity-building activities for both the Houston and Temple research projects.
- The review and analysis of existing data sets with collaboration from other state agencies and organizations providing services to people with disabilities.
- The collection and analysis of BRFSS-Disability Module data for Texas.
- The surveillance of condition-specific injuries (e.g., TBIs, SCIs, etc.).
- The continued development of a "one-stop-shopping-center" for the prevention of secondary conditions on the world wide web.
- The completion and distribution of the Statewide Strategic Plan for the Prevention of Secondary Conditions.

Researchers at the Ray Marshall Center asked interview respondents about the goals and objectives of the project and what outcomes they expected to result from their

[22] Funding cannot be released until NIH IRB approval. According to the TDH, this has been articulated to all project partners.

efforts on the project. The project partners echoed similar objectives for their respective pieces of the project and articulated various outcomes they expected to achieve by Year-Four. These included:

- Validation of the use of community-based facilitators who are trained to address the needs children with disabilities in their area.
- Improvement in the health and well-being of research project participants.
- Improvement in levels of parent satisfaction.
- Increased skill levels for both project partners as well as the families and children involved in the research.
- Increased knowledge and expertise that transfers from one setting to another (e.g., urban to rural).
- Increased comfort levels with telemedicine technology.
- Increased consultation with other independent school districts.
- Demonstration of the cost-effectiveness of telemedicine technology.
- Increased collaboration among members of the educational and medical communities.
- Increased levels of parent participation.
- The ability to pick up a telephone and obtain all the information needed on a child in one call.
- Improvement in the knowledge and understanding of the disabled population in Texas through the use of data.
- Increased knowledge and awareness surrounding the prevention of secondary conditions in Texas.

4.2. Other observations

Interviews with project staff and partners provides a basis for several broad observations about the On the Right Track project.

Project focus. Each project team member voiced an understanding of the overall purpose of the project as well as their particular contribution to the process. In addition, the vast majority were clear about why they were involved in the process and who they expected to benefit from the project – children and families.

Adaptability/Flexibility. Interviews highlighted the flexibility of those involved in the project. Staff and partners seem willing to take the time necessary to plan and execute activities that will prove most beneficial for the children and their families. Revisions to the Work Plan were made when it became apparent that the original time frames for the Houston and Temple research projects were unrealistic. Project staff appear well informed of the barriers surrounding the project and are amenable to taking

the time necessary to design activities serving the needs of all partners and not just a select few.

Commitment. There exists a high level of commitment to this project not only for the sake of research but more importantly for the long-term impacts a project of this type can have on the prevention of secondary conditions among children with disabilities. Each project team member spoke to the importance and value of a project of this type for children and their families.

4.3. Year-Three Evaluation

Researchers at the Ray Marshall Center will also conduct the evaluation of Year-Three efforts for the *On the Right Track* project. The priorities for Year-Three involve:

1) Evaluation of the extent to which project **Goal 1: Science** is being addressed. Activities will include:
    - Interviewing project staff and partners
    - Examining data (e.g., Behavioral Risk Factor Surveillance System) to address whether gaps exist around meeting project objectives
    - Evaluating the results of the focus group interviews with project participants and service providers in the Harris and Bell County research projects to determine whether the projects are meeting plan objectives

2) Evaluation of the extent to which project **Goal 2: Service** is being addressed. Specifically, researchers will focus on an evaluation of the implementation of the health promotion and awareness programs administered by the "*On the Right Track*" project. Activities will include:
    - Reviewing the training and educational materials, as well as the project web site to assess whether plan objectives are being met

3) Evaluation of the extent to which project **Goal 3: Leadership** is being addressed. Activities will include:
    - Reviewing of the implementation of the project's strategic plan

Based upon the review, assessing the performance of project staff and partners as well as the Advisory Committee to identify gaps (if any) and to provide timely feedback on such gaps so that corrective measures may be employed.